King's Fund

Carers Impact Project in Southwark

Report on the focus groups and interviews conducted with carers in April-June 1997

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Appendix 1: Summary of Characteristics

1 Introduction

1 a) Who we spoke to

The research exercise involved 52 carers. There were two focus groups with a total of 13 carers attending and 37 interviews involving 39 carers. One man and 12 women attended the focus groups and 13 men and 26 women were interviewed (one-to-one).

The age range of the carers was 30-80+ years with the majority in the 45-59 year age group (33%).

Almost three-quarters, (38) identified themselves as White/British with a further 5 White/Irish. The remaining 8 identified themselves as White/European, Black/African, Black/African Caribbean, Asian/Bangladeshi, and one carer preferred not to identify herself.

Most carers were married or in a permanent relationship (30). Seven were either separated, widowed or divorced and 15 were single. The most common relationships with the person cared for were those of parent, spouse, son or daughter. Some were caring for a brother or sister, or partner, and one was caring for their employer.

Further details about the carers involved are given in Appendix 1.

1 b) (i) The interviews

The individual interviews were carried out with the aid of a semi-structured schedule. This was divided into five main sections:

- The history of the caring relationship and the nature of the current caring task.
- Pathways to services - how the carers found out what was available and which had proved to be the most useful sources of information.
- Carers' experiences of assessment and the implications for support.
- Their experience of services.
- The impact of services on carers' lives and any gaps identified.

On average the interviews took one-and-a quarter hours to complete. The actual time varied according to the complexity of the caring history and the range of services currently received.

1 b) (ii) The Groups

A simple format was adopted for the groups, comprising:

- A warm-up exercise based upon a written 'cameo' - a fictional account of a carer incorporating some common dilemmas and problems. In smaller groups, the participants were asked to consider the factors which helped the cameo carer in their caring task and the factors which got in the way. They then fed back their points to the whole group and these were recorded on a flip chart. Previous experience with cameos in a focus group setting had shown that this exercise was helpful in enabling carers to put their own experience into a broader context and to develop a more general perspective on preferred outcomes.

- Individual feed-back from the group members on similar lines but drawing explicitly upon their personal experience. Their replies were recorded on the flip chart.

- A brainstorming exercise around the question, *'If you could improve the situation for carers like you in Southwark, what would you change?'*. Ideas were listed on the flip-chart.

1 c) Presenting the findings

In presenting the findings, we have broadly followed the structure adopted for the interviews. Thus we consider in turn the carers' backgrounds, their experiences of access to services, with special reference to the assessment process, and their views about services currently received. The analysis is based upon the interview data, amplified with material from the focus groups. The 'Key Messages' section at the end summarises the carers' views about desirable outcomes and the factors in their situations which help or prevent these being achieved. Some issues specific to current service provision in Southwark are then outlined along with the carers' suggestions for needed improvements.

2 What the carers told us

2 a) Caring background

2 a) (i) The person cared for

A total of 55 people (22 men and 33 women) were being cared for since some carers had multiple caring responsibilities. Five were under 18 years old, but the majority were older people (14 aged 60 to 74 years and 20 aged 75 years or over). Most lived in the same household as their carer. Whilst many of those cared for could be classified in more than one client group, people with physical or sensory disabilities were the client group most often identified (35 individuals). People with mental health problems, including dementia, formed the next largest category (22 individuals). Seven people had learning disabilities, one had HIV/AIDS and one had alcohol or drugs problems.

Two carers had cared for people who had subsequently died. Information is included for the people cared for prior to their death.

2 a) (ii) Length of time caring

The length of time that the carers had been caring varied considerably. Some had been looking after adult children with disabilities for up to thirty years but most had been caring for between three and ten years. There were no very recent recruits to caring. In some cases, the carers had begun to care following a specific event such as the birth of a child or an accident to the person cared for. For most, however, the role had developed gradually with the deterioration in health of the person cared for.

2 a) (iii) Caring tasks

Six of the people cared for could perform no personal care task for themselves, including turning themselves over in bed, and were thus totally dependent upon the carer and upon the professional services which came into the home. At the other end of the spectrum (in terms of the level of physical support required) was a young adult with hearing impairments whose mother provided emotional support and occasional interpretation. Emotional support, supervision and companionship were also the main components of caring for the younger people with mental health problems within the group.

Among the physical tasks performed by carers, lifting was frequently mentioned and posed specific problems. Some had hoists to help them but others were coping unaided. Several instances came to light in which paid staff coming into the home or the staff providing school transport were unable to help with lifting because of the health and safety regulations under which they worked. The result was that the carers were putting their own health and safety at risk by doing the lifting that other people would not do. Several had developed back or other injuries as a result.

The more heavily dependent people tended to be those that shared the household with the carer. Where they did not share the same household the demands were often more in the nature of supervision, taking responsibility for financial matters, medical appointments and household chores, rather than personal care tasks. However the emotional drain of the anxiety caused by this level of responsibility should not be underestimated.

Where the carer was the spouse or partner, a notable part of their caring role was to keep up the spirits of the person cared for. A number of the adults with physical disabilities suffered from depression as a result of their changed circumstances, and the carers were called upon to provide a great deal of emotional support.

Pressures were obviously increased for carers with multiple caring responsibilities.

One woman in her seventies cared for her mother in her nineties and her husband with Parkinson's Disease. This carer herself had health problems and needed to use the bath hoist to assist herself in and out of the bath. She and her husband helped each other where they each had difficulty, jointly managing tasks such as getting her mother into a wheelchair.

Special difficulties were experienced where the carer had responsibility for people in widely different age groups and circumstances. This was illustrated by a carer who was simultaneously looking after her young son with physical and learning disabilities and her mother in the early stages of dementia. Managing her son's busy schedule of activities and therapies while providing supervision and support for her mother consumed all her physical and mental energies.

2 a) (iv) Changing demands over time

Those carers who had made an abrupt transition into the caring role following a specific event tended to compare the demands made on them at that point with the 'normality' of their previous lives. Subsequent changes in the demands which they faced tended to be seen as insignificant compared with that first tremendous change. Nonetheless, this group of carers had had differing experiences, some finding that demands had lessened as the person cared for improved and/or adjusted to new circumstances while others experienced growing demands linked to the deterioration of the person cared for.

Some of the carers who had gradually assumed the role described a similar picture of waxing and waning demands but for the majority who were looking after adults with physical disabilities and mental health problems there was a clear trend towards an increasing burden of care, particularly where the person cared for was older. Gradual physical deterioration, memory loss and declining confidence in performing tasks for themselves shifted increasing responsibility onto the carer.

Where the carers were themselves older, they worried about their own health and strength, and their ability either to continue caring or to meet the costs of residential care if that should be required by the person cared for. Carers of adult children had particular anxieties about the longer-term future if they became unable to care.

2 a) (v) What got them down

For many carers the change in financial circumstances was a source of regret. A few who lived in separate households could not afford to provide as much support (telephone calls and visits) to the person cared for as they would otherwise have done. Others had found that lack of money placed severe restrictions on their social and leisure activities. Reduced circumstances were in some cases linked to a loss of employment which was also missed for the companionship and personal challenges which it offered.

A number mentioned their loss of friends and social contacts as a result of caring. One said, *"I haven't got a life any more".* Before his partner became dependent upon him, they used to go out together. He especially enjoyed playing golf, and regularly used to meet friends on Friday afternoons for golf and a drink. Now Fridays were a pressure point for him. He could not afford to join in the activity, but he knew that the others continued to meet.

Inadequacies in the environment got carers down. One family did not have enough room to manoeuvre the wheelchair within the house. Another had constant battles with the local Council over rubbish on the pavements that caused problems for wheelchair access.

Carers' own diminishing health and capacity to cope caused frustration and anxiety in several cases. One carer said she had bad hands and so could not lift her mother. This made the physical caring more difficult and also made her worry in case her mother should fall and she would not be able to lift her. One carer in his 80's was very concerned about how long he would be able to drive his car which was a lifeline to himself and his wife, enabling them to go out and do their shopping. He felt that their lives would be greatly diminished without it.

For many carers, the greatest regret was the lack of time for themselves, and the constant emotional drain. One woman said *"I don't have any life. With mum and my son, there's nothing left for me in the middle".* Another said, *"Life is 100 miles per hour but never for me. I always feel I'm last on the list".*

Frantic activity was often combined with a predictable and relentless routine, causing one carer to refer to the *"sheer bloody tedium"* of his daily life.

Dealing with outside professionals was another problem area. Communication breakdowns and poor liaison caused anxiety and stress, and carers clearly disliked having to repeat the same information to different people. They were sometimes left to fill in at short notice when services were cancelled or help failed to arrive. Arranging transport and making appointments for services featured as a significant additional element in their workload. Some carers felt that they had been fobbed off by the Social Services Department, and the struggle to find help got them down.

2 a) (vi) What they enjoyed

Some carers endured their caring role and found little to enjoy about it even if they had an affectionate relationship with the person cared for. In such cases, they were motivated by a sense of obligation but mourned their loss of independence. Most carers, however, were able to say something positive about their caring experience. Many said that they loved the person cared for and therefore cared without resentment and regret. The quality of the relationship that predated the caring role seemed to have a marked effect on the carers' ability to find aspects of caring enjoyable. A few carers said that they were repaying a debt for past care, and did so gladly, while others said that they knew the person cared for would do the same for them if their positions were reversed.

There were challenges which some carers found enjoyable. One particularly enjoyed rehabilitating the person cared for following an accident; someone else enjoyed learning to cook; and another liked finding things to amuse her father with dementia. A carer looking after his spouse with physical disabilities described how in the early years they were full of enthusiasm to meet the challenges, but that their energy had dissipated over the years. They nonetheless enjoyed each other's company and were great friends.

A parent carer described her pleasure in seeing her son grow. She said that she had read the literature and knew that the future was not all bleak. She had done more voluntary work because of him, which gave her self-fulfilment and joy.

2 b) Access and assessment

2 b) (i) First contacts

Very few carers felt that they had had a clear idea at the beginning of what services were needed for the person cared for or themselves, or what was available. One said *"You're so concerned about doing things for her you don't* *think to ask who can I ask for this or that?"*, and another, *"I thought I could do it all on my own - I still think that sometimes".*

The passivity and uncertainty of many carers in their contacts with formal services emerges strongly from the research. The notion of carers realising a problem, identifying a need for help and going out to find it greatly oversimplifies their experience. Contacts with services were often accidental or inconclusive. Carers who made preliminary telephone calls to the Council were easily put off by being passed from department to department or by being given a list of numbers to ring, and few had the confidence to press their GP for information about the help they needed, even though almost all were in touch with their practice at some point.

A large number of carers (16) identified an episode in hospital for the cared-for person as the first point of contact with services. In some cases, this resulted in a thorough review of the help needed to care at home.

One carer remembered, for example, the excellent support received from a District Nurse upon his wife's discharge following a sudden paralysis. She analysed the situation and contacted the relevant services directly. Without her involvement, he confessed, he would not have known where to start.

Others were not so lucky. Carers of adults with mental health problems seemed particularly poorly served with advice and help during and after hospital admissions.

One such carer remembered that no-one had come to talk to her about her needs and that although she clearly signalled during ward rounds that she was in trouble, the medical staff refused to listen.

Where there was no specific crisis to activate services, carers often coped for long periods without seeking help and often without much awareness that help might be available.

A typical example was a woman caring for her elderly mother who felt that she could cope on her own and knew that her mother would resist help in any case. A deterioration in her mother's condition eventually persuaded her to contact her GP who arranged an assessment. It was only at this point that she became aware of benefits to which she might be entitled, reflecting many other carers' experiences of delayed access to benefits because of limited information.

Comparatively few carers had taken a proactive and systematic approach to finding help. One woman had developed a large network of contacts and information sources to help her cope with her daughter's skin condition. She acknowledged, however, that this had involved persistence, confidence and a large telephone bill. Most carers, in contrast, had little energy to expend on seeking information and were easily deterred if their initial efforts were fruitless.

2 b) (ii) Sources of information

Hospitals and GPs were considered useful for medical/clinical information but not as a general source of advice about services that might be available. Some carers considered that their GP did not have enough specialist knowledge of the condition of the person cared for but most simply believed that he or she was simply too busy to be asked. Several carers had had GPs who were not helpful, and two had changed to a more sympathetic practitioner. The most unhelpful experience was recorded by a carer who said she had had no information, no explanation and no understanding from the GP. On the other hand, six carers did report helpful contacts with their GPs which produced information, an assessment and/or a referral to a support service. Most carers shared the same GP with the person cared for and in these cases the GP was aware of the carer's responsibilities. Where the GP was not shared, however, the carers did not believe that the GP knew about their situation.

Those who had had contact with a social worker mostly found them helpful, but the contact was usually later on in their caring role rather than at the initial stages. Friends, relatives, and other parents of children with disabilities proved to be important sources of information to some carers. Where this was the case, they commented that this was a rather ad hoc way to acquire crucial information which should have been available more readily from official sources.

Several carers identified Southwark Carers or local carers groups as useful information and access points for services. One man remembered that he had found out about Crossroads via Southwark Carers and that someone had helped him complete a Motability form. Others received regular information through newsletters but had not made a specific contact to ask about services. One carer did say that the information from Southwark Carers was useful until she tried to put it into practice, only to find that the details were out of date, or the services described were impossible to get.

Perhaps the most effective source of information about services was a professional worker who took on the task of activating services and benefits for the carer and person cared for. The example of a District Nurse offering this support after a hospital admission has already been given. Other carers mentioned a counsellor, a local advocacy service and benefits agency staff in this role.

2 b) (iii) Social Services Assessments

A clear majority of carers (25) said that someone from Social Services had been to see them within the past two years to talk about the help they needed and one more had had contact just over two years ago. Most of the carers identified the contact as an assessment but not all were comprehensive assessments of the social care needs of the person cared for and in only two cases were the carers needs explicitly assessed and a record made. Some of the assessment visits were by an Occupational Therapist looking at the need for aids and adaptations; and one was looking specifically at a child's needs for respite care. In other cases, some services were already in place and the assessment focused upon the addition of a new element, such as day care or respite care.

Ten of the assessments were made at the carers' request, three requiring some persistence on their part. In one case, the carer was initially told on the phone that the person cared for did not need an assessment, and another was informed that her son was not a priority. The third carer had rung Social Services to request an assessment when she found out about the Carers (Recognition and Services) Act but had no reply for several months until she approached her GP whose intervention prompted an assessment the following month. Another carer was less fortunate, having had no assessment despite her own efforts at self-referral and three letters from her GP.

In 15 of the 25 assessments, the carer knew that a written record had been made of the needs of the person cared for, and nine had received copies. Two carers knew that a written record was made of their own needs and one received a copy. The other did not because she and the social worker agreed that she had no special needs. One woman whose mother was assessed by a social worker was promised a further assessment of her own needs but heard no more, and a man was left with a carers' self-assessment form to complete but *"had never got around to it"*. The notion of having their needs assessed separately was evidently a novel one for several carers and one person expressed amusement at such a fanciful idea.

13 of the carers were very positive about their experiences of the assessment and about the person who came. The comments included, *"brilliant"* and, *"she was a very caring person"*. Most of the remainder judged the experience to have been satisfactory but five made negative comments. In one case this was because the social worker's attitude had been seen hostile, and in the others because the assessment had not resulted in tangible benefits *"They seemed nice and helpful but when nothing happened, I regarded it as a complete waste of time"*. One carer reported a good experience of assessment by a social worker followed by an unsatisfactory encounter with the Occupational Therapy Services, by whom she considered she had been treated rudely and abruptly. More positively, a woman who had broken off all contact with Social Services following an upsetting incident several years ago was pleasantly surprised, on re-establishing contact to negotiate extra respite care for her son, to discover how helpful and constructive the assessment process had been

11 of the 25 assessments had resulted in tangible results for the carer in terms of additional services for the person cared for. These were not the only positive outcomes reported. Feeling better supported and informed, being reassured that an existing level of provision would be maintained rather than reduced, being able to get your point of view across, and negotiating adjustments to services were all identified as benefits of the assessment process. Carers who were satisfied with the level of support they were already receiving were nonetheless pleased that the situation would be subject to regular review through assessment.

2 c) Carers experience of services

2 c) (i) The range of support received

The carers were asked about the support they currently received. Interviewees were prompted with a written checklist while focus group members were invited to describe their circumstances to the rest of the group.

The individual interviews revealed a wide variation in the type and amount of help received.

Complex packages of care were described by two older men, both caring for their wives who were suffering from acute and disabling terminal illnesses, requiring high levels of personal and nursing care. Key components of the packages were home care, nursing care in the morning and at night, day centre support, extensive adaptations to the home, holiday respite, night sitting and transport. A carer of a man with severe disabilities was also supported by 24-hour domiciliary care.

At the other extreme, in terms of the intensity of the support received, were three carers of adults with mental health problems. Here the options for support appeared limited and the carers were experiencing feelings of isolation and uncertainty in their caring role.

One carer said that the only significant source of help had been occupational therapy for her partner at a local hospital but that this had now been discontinued and they were now essentially coping alone. Another had pushed for his brother to be offered a place at a voluntary sector day centre but he went there only occasionally and the carer was desperate for other affordable options which could offer him social contact and stimulus. In several cases, aids and adaptations within the home were the only form of support received.

In between these extremes, the majority of interviewees were caring for people with physical disabilities and/or mental impairments who needed a moderate and consistent level of support. The underlying trend, however, was towards greater dependency, particularly where the person cared for was elderly. Typically, the staple features in the pattern of support were a day centre place for one or more days each week, adaptations to the home and some continuing help in the home through home care or a sitting service. Where the person cared for was older, access to the chiropodist and optician appeared good and these services were often provided conveniently at the day centre.

The small number of carers of children with disabilities relied upon the education service for the organisation of schooling (including transport) and therapeutic services. These appeared to be generally well co-ordinated but problems were noted with interruptions to speech therapy, and one mother was concerned about physiotherapy being withdrawn from her son's programme. Her anxiety was not simply about the loss of a beneficial service but also about the possible threat which this represented to his status as a statemented pupil.

A number of the people interviewed had required the services of the Housing Department to be rehoused in the past, and one was in the process of negotiating rehousing. For some this had been a relatively trouble free process but one carer had had such difficulty that she had had to contact her local Councillor and MP before the matter was resolved; and another had experienced long delays and unhelpful and obstructive staff. One carer wanted to buy her property from the Council in order to build an extension but so far had been refused. Major adaptations such as stair lifts or hoists had to be negotiated with the landlords of rented properties. Two carers whose landlords were housing associations were refused a stair lift in one case and an extension in the other because of budget limitations but others had encountered no problems.

The spectrum of support services received by the focus group members was different in some respects. Because there were no carers who were currently looking after terminally ill people, there were no examples of intensive support through complex care packages. Some carers were looking after people with behavioural problems or acute anxiety related to mental illness. In these cases, intermittent breaks were provided through hospital admissions or respite care but the carer received little continuous support or emergency back-up. One said that the Community Psychiatric Nurse did call from time to time but that nobody came regularly and that she had to go out to seek help when necessary. In contrast, a carer of an adult with learning disabilities and acute behavioural difficulties received consistent support through her daughter's attendance at a day centre throughout the week.

More carers in the focus groups than in the interview group were living separately from the person cared for, usually in close proximity, although one carer lived out of the Borough and travelled regularly to visit her son living at a residential care facility in Southwark. These carers were supporting the cared for person in parallel with a range of formal services, typically the home care and District Nursing Services. However, living apart did not seem to lessen the anxieties of caring since the carer felt responsible for co-ordinating and supervising the support provided, for example by ensuring that medication was properly administered and that agreed actions were followed through.

2 c) (ii) Help from the GP

The role of the GP in providing support for carers was of particular interest in the study in Southwark. With a few outstanding exceptions, GPs did not emerge as a source of continuing emotional or practical help. Their role was mainly a responsive one, producing information or making referrals when asked but rarely taking the initiative in providing help or encouraging the carer to turn to them for support. The air of crisis which surrounded the GPs' own work (illustrated by routine difficulties in making appointments and the near impossibility of obtaining a home visit) added to the carers' hesitancy in 'bothering' them about matters which were not strictly medical. That said, there were several examples (as noted above) of GPs providing a useful referral or contact, on request, which resulted in additional practical support for the carer.

Within the common constraint of their busy workloads, GPs appeared to vary considerably in their attitudes to carers and the seriousness with which they viewed their circumstances. Some were described as always pleasant and helpful while others *"couldn't wait to get rid of you".* Having an unsympathetic GP added to carers' sense of isolation and undermined their confidence in seeking help.

Despite this generally disappointing picture, there were promising examples of good practice in increasing carer awareness among primary health care staff. A few carers attended support groups which were sponsored by their local practices and one reported that each new member of staff was required to visit the carers' group as part of their induction.

2 c) (iii) Choice for the carer

The carers in the interview group were asked a series of questions about the extent to which they and the people they cared for had been able to exercise choice over the support which they received.

First they were asked whether they had been able to choose the right combination of services to help them in their caring task. In other words, had they been able to choose the pattern of services which actually matched their needs? 12 felt that the combination of services was about right, although half of these qualified their answer in some way. For example, one carer said that although the services were in place, nothing seemed to work all the time, mainly because of difficulties with transport. Another said that because of cuts in the local Health Trust, he and his wife were never sure which nurse would turn up to provide morning and twilight care. These points are related to the issues of quality and flexibility which are discussed below but they are worth highlighting here because they demonstrate that even though a good range of support may be offered, its value may be diminished by poor access or low consistency.

A different point made by a parent carer was that although she had been able to activate a number of different services for her son, there was no support which was directed specifically towards meeting her own needs. Two carers felt that they had had choice only as a result of their own efforts to investigate the possibilities and obtain suitable services.

The concept of being given choice was questioned by some of the carers. One said: *"Choosing services - it's a grand term. It's difficult to know what you're choosing between and to make a choice".* She believed that the services she would choose for her son would not actually be available. Others believed that choice was not applicable because it was a question of accepting what was on offer.

Those who responded negatively to the question believed that there had been no effective choice and that the combination of services received was inadequate for their needs. One made the point that there was no co-ordinating point to help plan and activate the support required. Some carers were unsure about their reply because they felt badly informed about the range of support which could be available, and others judged that the question did not apply to them because they were not receiving services.

The carers were also asked whether they had been offered any choice with regard to individual services. For example, had they been able to choose between different day centres or alternative home care providers? Only two carers recollected such a choice being offered. One had been given a list of day centres for her mother and settled for the one closest to her home. The other woman had been to look at several residential homes but found that only one had a place available. No-one had been offered a choice of home care providers, although one had pressed for a change in the regular worker.

The remainder of carers had either accepted the service offered or had exercised choice by making independent arrangements. Among the latter were two carers who had done their own research on alternative respite arrangements for the person they cared for.

The opportunity to choose between alternative services did not appear to be an important issue for the carers of older people who were more concerned that the services were reliable and flexible. For the carers of younger adults and children, however, the precise match between the service on offer and the interests and abilities of the cared for person was more crucial. One carer who had rejected a local authority day centre for his mentally ill brother on the grounds that the other people attending were too severely ill had been able to arrange a voluntary sector day centre through his social worker. He did emphasise, however, that this choice had not been freely offered and had involved persistence on his part.

2 c) (iv) Choice for the person cared for

Most carers felt that the people they cared for had not been able to make independent, direct choices about the services which they received. This was either because their physical or mental condition made such choices difficult, or because circumstances were seen to dictate the services required. Also, the unit of carer and cared-for person was often perceived to be so close that it was impossible for one party to take decisions without reference to the other. Many had taken on the role of guardian and interpreter of the cared-for person, ensuring that their preferences were taken into account when support was organised.

One carer, for example, described how she 'talked things over' with her son who had no speech but was able to communicate through his computer and by means of body language. In this way, she was able to elucidate which aspects of his care he enjoyed and which were less satisfactory.

Similarly, other carers described how the cared-for person exercised a subtle influence over the services they received by the responses they made. For example, the number of days at a day centre or the frequency of respite care might be adjusted according to their reactions.

One carer was sure that the person cared for did have choice because he would not do anything that he did not want to do; and another person cared for had asserted himself by adapting the package offered (help with bathing) to meet his needs (by requesting that the worker should wait outside the door rather than be with him in the bathroom, thus ensuring his privacy and but also providing security in case anything went wrong).

Many carers recognised a tension between their own needs and those of the person cared for, although most believed that a compromise had been achieved. This tension usually arose from the carer's need for support and a break versus the cared-for person's preference for being looked after exclusively by the carer in the familiar environment of home. Several recognised that their parent's or spouse's acceptance of day care or respite care was primarily an acknowledgement of the carer's needs. On the other hand, there were carers who had sought a lower level of support than they would ideally like because they were reluctant to stretch the cared-for person's tolerance of formal services. At the extreme, this had created situations where carers were receiving little or no support because of the refusal of the cared-for person to accept any form of intervention.

2 c) (v) Issues of flexibility and cost

Most of the carers considered that their use of home care or day care services had not been limited by cost, but one carer had been unable to afford the home care offered and therefore had none. Another carer complained that the weekly cost of home care consumed quite a high proportion of her budget, but the majority view seemed to be that the charges were reasonable and fair. Similarly, only one person had stopped going to respite care because of the high charge; and in another case the couple had not taken up the offer of respite because although they could afford the charge for the person cared for, they would only go together, and would have to pay a further charge for the carer which they could not afford. In those cases where the carer had made respite arrangements independently, an agreement had usually been reached with the Council about sharing the costs, or the costs were met with the help of benefits. Most worries about the costs of services tended to centre upon the uncertainties of future provision rather than upon present care. Predictably, carers of older people were particularly prone to anxiety about how the costs of residential care might be met.

Although in most cases, the services on offer were seen as affordable, the carers did emphasise that the costs of caring were considerable and tended to be unrecognised. Extra clothing, heating and laundry costs were frequently mentioned as burdensome, and were difficult to meet within the available allowances. Moreover, a few carers were frustrated at being unable to afford the kind of help which they felt to be appropriate in their own circumstances but which fell outside the parameters of formal support. For example, one carer had discovered that his brother enjoyed going to the local gym but was unable to afford regular sessions.

Transport emerged as a far more significant factor than cost in determining access to services. The local authority day centres and a special school were the only facilities which provided transport to and from home. Otherwise carers had to make their own arrangements.

Day centre transport was generally seen to be reliable and satisfactory. There were, however, occasional problems about its flexibility.

This is illustrated by the predicament of one carer of an older person with mental health problems who had been regularly collected at 8.30-9.00am for a day centre session which started at 11.00am, thus causing unnecessary complications to the morning routine. A mutually convenient time was subsequently established after repeated requests from the carer and the arrangement now appeared to be working satisfactorily.

A rather different problem was described by two carers who lived near the top of blocks of flats. They complained that the day centre transport staff refused to come upstairs in the lift to collect the cared-for person, thus leaving them to manage the difficult manoeuvre of getting down to the ground floor when the transport arrived. One of the carers reported that the reason for this was that transport staff had previously been attacked in the lift, but pointed out that it was hardly satisfactory to expose the carer and the cared-for person to the same hazards.

Otherwise, the staff providing the day centre transport were widely described as friendly and helpful, with one exception where the carer complained that the elderly woman for whom she cared had been made to feel embarrassed by an incontinence 'accident' on the ambulance

Transport was considerably more problematic where it had to be arranged independently. Most carers were without cars of their own or unable to use them for carrying the cared-for person, therefore, every journey outside the home had to be planned in advance. Timing was particularly important for keeping hospital appointments or ensuring that the cared-for person reached college on time but efficient organisation was also required in order to take part in social activities. A few carers had to make quite complex arrangements for the cared-for person to travel to a respite care facility outside the Borough; this might involve different forms of transport and multiple tickets. But however meticulous the carers were in planning ahead, they were often let down by unreliable or over-stretched services. Dial-a-Ride was criticised for making insufficient provision for wheel-chair users (one carer describing her attempts to use the service as a *"nightmare"*) and was said to be unreliable and frequently unavailable at the times required. A few carers had taxi-cards which enabled them to use the black cab service at reduced cost but complained that it was difficult to locate a cab. The majority relied upon local mini-cab firms of varying efficiency. This solution was expensive and some felt that they were given low priority when arrangements had to be made for regular journeys.

In a small number of cases, transport difficulties were compounded by inadequate access to public buildings. One carer whose son had regularly attended at a computer course at Southwark college suddenly found that the course had been moved to a different building without a lift. He missed college for a whole term as a consequence, causing serious disruption to both the domestic routine and to his studies.

The other main arena in which flexibility was an issue was the provision of care in the home. For the carers, flexibility was a matter of attitude on the part of staff as well as the timing of services. For example, it was suggested that both District Nurses and Homecare staff needed to be more prepared to think laterally by attending to small details which might lie outside their specific remit (such as straightening mats to prevent a fall). Their training should perhaps help them to be alert to the whole picture as well as to perform particular tasks.

More generally, the carers wanted support in the home which was adequate in amount and provided at the most opportune times. There were many cases in which this happy combination had been achieved but some carers seemed to be stuck with a less than optimum pattern.

For example, one focus group carer was receiving homecare one day per week to help care for her elderly parents, both suffering from dementia, but expressed a need for this service on at least two days and for both mornings and evenings. Another carer interviewee explained that the overnight care which Crossroads provided would be more valuable to her if it could be replaced by evening care at the week-end since this would enable her to go out and meet friends.

Such carers seemed to lack confidence in re-negotiating their care arrangements, possibly because they feared appearing ungrateful or even felt that they might jeopardise the existing arrangement.

Adequate practical support in the home through appropriate aids and adaptations was an important dimension of flexible care where the person cared for had significant physical disabilities. An interesting exception to this was provided by a carer of a severely disabled adult who had minimised the use of adaptations in order to maintain a more normal environment. In general, however, aids and adaptations were used to smooth the practical routines of personal care and to bridge the gap between home and the outside world. The carers' experiences of the assessment of need by the occupational therapy services were generally satisfactory but there were instances where the aids and adaptations had not been up-dated in line with the deteriorating condition of the person cared for. One carer, for example, had had a bath-lift fitted in the downstairs bathroom when his wife was in the early stages of her illness but she had now deteriorated to the extent that she could not move downstairs. Pending the installation of a new shower/toilet, the carer had to depend on the day centre for giving her a weekly bath.

Access to incontinence supplies appeared to be generally satisfactory, with only one carer reporting a problem. In this case, the person she cared for had a bowel disorder requiring particularly heavy-duty pads which were difficult to obtain in adequate amounts from the District Nurse.

2 c) (vi) Issues of quality

- ***Home care services***

  Among those carers receiving home care services, there was widespread concern about the poor quality of provision by private agencies. Although several examples of good practice and good relationships were reported, it was common for carers to mention the poor timekeeping, low morale, lack of training and experience and lack of professionalism among the staff. The tendency for staff to rush away to the next assignment when tasks were completed rather than providing the full allotted period of care was a recurrent complaint. A lack of thoroughness in the personal care provided was an issue for some carers, one recalling, with some amusement, an occasion when his wife had been put to bed fully dressed.

Two carers who had had particularly bad experiences questioned the recruitment policies of the agencies involved. One comment was that the homecare staff had adequate skills for caring for people with slight disabilities but that they were overstretched where the person was severely disabled or ill and required an element of skilled nursing care.

- ***District Nursing services***

Several carers were unhappy with aspects of the District Nursing service. This emerged particularly strongly from the focus groups where more carers were living separately from the person cared for and where the quality of support going into the home was of great importance to their peace of mind. Carers complained that District Nurses rushed in and out, failed to co-ordinate their visits with the cared-for person's routine and were inconsistent in monitoring medication where there had been a specific agreement that they should do so. One carer described how she had to write copious reminders about her mother's tablets, which appeared to annoy the nurses but which did not resolve the situation. Lack of attention to detail was also criticised and this was seen as a consequence of the nurses' overloaded schedules. Better communication with the carer was another request, especially where the person cared for suffered from dementia; without these, the carer found it difficult to supervise medication and arrange appointments.

- ***Aids and adaptations***

In several cases, the aids and adaptations were the principal means of support and worked smoothly as part of the daily routine. When problems arose with their supply or functioning, however, significant disruption was caused to the carer and person cared for. Problems arose from excessive delays in the delivery of needed equipment, the malfunctioning of equipment and unsatisfactory repairs. One family had been waiting for over a year for a wheelchair to be delivered, and another had been waiting for a long time for a wheelchair to be taken away to be repaired. Several months often elapsed between the ordering and delivery of equipment.

Two households with major pieces of equipment (a hoist in one case, and a stair lift in another) had experienced repeated faults and breakdowns for more than a year. The hoist had now been properly mended but the stair lift still caused intractable problems. Both pieces of equipment were essential to the functioning of the people cared for.

2 c) (vii) Liaison between service providers

Most carers within the interview group were sceptical about whether the different service-providers involved in their own situation communicated with each other. In particular, they suspected that little liaison took place between their GP and Social Services, and where the cared-for person regularly attended a hospital clinic or (in one case) a hospice, there were further doubts about the extent of the communication between primary and secondary health care staff. This led to confusion for a few carers about the main point of co-ordination for medical treatment and about where to turn in a crisis. In one case, the carer complained that a lack of co-ordination had had an adverse effect upon the treatment of an infection contracted by his terminally ill wife.

Some concerns were recorded about the extent to which Social Services communicated with the Housing Department when problems of accommodation were exacerbating the condition of the person cared for or where they inhibited access to services.

Interestingly, those carers who did believe that services liaised with each other, tended to identify negative rather than positive consequences for themselves and the person they cared for. One carer, for example, felt that the services had banded together to fend off a stream of complaints which she had made about her husband's care and another believed that information hostile to herself had been fed to a hospital where her mother was an in-patient.

Some were more concerned with the effectiveness of the services' liaison with themselves as carers. This was raised most frequently in connection with the District Nursing service.

2 d) The impact of services

2 d) (i) More time for themselves?

Fourteen of the carers in the interview group considered that the services which they received allowed them more time for themselves. The remainder were divided between those who were not receiving regular support, those who felt that services did not significantly affect the time spent caring, and those for whom the services enabled them to get on with other tasks such as paid employment, shopping and housework.

Reliability, regularity and consistency of service delivery were the key factors which enabled carers to plan activities outside their caring role. Day care and regular sitting arrangements were the services most often cited as meeting these criteria. These could be incorporated into the daily or weekly routine and were not subject to the periodic interruptions which characterised educational provision. The *amount* of guaranteed time off which the carers were given was also important. Thus the benefit of day care to the carer could be seriously reduced if transport arrangements squeezed the time the cared-for person spent away from home. And several hours of support from a sitting service might be needed to enable the carer to do more than catch up with neglected chores.

However valuable the time liberated for the carer during the week, most expressed a need for a complete break at regular intervals. Holiday respite featured as an essential element in the coping strategy of several carers in the interview group. Confidence in the quality of care provided was essential to their own peace of mind, and none of the carers seemed to harbour doubts about the facilities they used. Unease about respite was more likely to be provoked by the reluctance of the cared-for person to accept it, although there were several examples within the study of respite care which was eagerly anticipated and enjoyed by the person concerned.

Given the importance of holiday respite to the emotional and physical well-being of carers, it is perhaps surprising that it was not more widely used by the carers. Just over an eighth of carers in the interview group had access to this service, compared to more than a half using day care.

Among the focus group participants, none had regular, planned respite care. One had time to herself when her husband with mental health problems was admitted to hospital in a crisis but this was necessarily unplanned and unrelated to the carer's own needs.

The reasons for the limited use of holiday respite did not emerge clearly from the study. One of the carers reported having to wait but others did not have difficulties in obtaining this service once they had asked for it but our impression is that several were unfamiliar with this service and were perhaps unlikely to request it spontaneously. Other carers did know about the service but were committed to providing the care at home or felt that residential care was not the most appropriate respite option for the person cared for.

Carers of adults with mental health problems stood out as the group least likely to be receiving support and respite which allowed them time for themselves. Such carers complained of a lack of suitable alternatives to day care for adults who felt uncomfortable in group situations and who required more individual stimulation. They also considered that the social work support following acute episodes was unfocused and of short duration, and the response of the health services was sometimes unhelpful. But over and above the inadequacies of the services, they felt a huge personal responsibility for coping with the anxiety and emotional needs of the person cared for, to the extent that some felt unable to remain out of sight for more than a few minutes. In these circumstances, the carer needed personal support in order to be able to leave the situation from time to time. One carer who had obtained this support with the help of an experienced counsellor felt that her husband had also benefited from her own more relaxed outlook. Others, however, remained stoically in an emotionally draining situation.

Parent carers did not view the schooling provided for their children as an 'extra' which created more time for themselves. Services outside of school hours were more likely to be seen as having added value for the child and other members of the family in enabling them to *"have a life like other people"*.

2 d) (ii) The impact on the person cared for

Most carers believed that the services received were of direct benefit to the person they cared for. In some cases they made the crucial difference between being cared for at home and long-term residential care. Carers of younger adults highlighted the range of activities on offer at day centres or college, keeping the cared-for person stimulated and active, and providing opportunities to learn. One carer said that without the support of these facilities, she would have been quite unable to occupy her son. As it was, he was never bored and was full of self-confidence. A carer of a young child with physical and learning disabilities believed that the extra support he received through respite and regular befriending allowed him to lead as 'normal' a life as possible.

Being in the company of others was generally considered important for the cared-for person, whether the contact came through outside activities or through people coming into the home.

One man said that life for his wife who suffered from dementia would be horrible without the day centre where she was part of a group and had made a particular friend. Another believed that the hospice day centre which his wife attended was a lifeline for her, allowing her to pursue her artistic interests in congenial company. A third carer said that the carers and nurses who came into the home made the environment livelier and more interesting for the older woman she cared for and that they often enjoyed 'having a good giggle' at the day's events.

The benefits to the cared-for person were substantially reduced where the quality of the service was judged to be unsatisfactory or where the service had been activated against their preferences. Even in these cases, however, there were thought to be indirect benefits through the relief of pressure on the carer which in turn made their relationship easier.

2 d) (iii) Impact upon the relationship of the carer and the cared-for person

Most carers who received regular support believed that there had been positive spin-offs for their relationship with the person they cared for, although some had grown so familiar with the caring routine that they found it difficult to conceptualise the impact of services in this way.

The reported benefits were increased patience and stamina for the carer; emotional support for both parties through the involvement of others; more to talk about together and a calmer and more detached perspective on the carer's part towards the demands being made. Illustrating the latter point, one woman said, *"Yes, it had made me realise that she is very old and that she is very sick I can see the fear in mum. Understanding this has made it easier to cope".* An easier relationship in turn reduced the level of stress experienced by the carer, making it more possible to continue to care.

Some carers, however, resisted the idea that the services had made a difference to the relationship and emphasised that they had always got on well.

3 Key Messages

3 a) Desirable outcomes

The focus groups were a particularly rich source of information about the outcomes desired by carers. Through the cameos they were able to apply their own experience in order to identify positive changes needed in the life of the person depicted. These were often at quite a general level but indicated the kinds of impacts which they considered important. The carers in the focus groups and the interview groups were also encouraged to think about changes which would be helpful in their own situation.

The outcomes which they identified as important for themselves and others were:

Desirable Outcomes	**Comments made in the groups and interviews**
Good access to information	More awareness of services that are available.
Emotional support	Counselling would help. I would like a person to listen and a person to care. Something like the Samaritans but someone who cares - it's a lonely world.
Having a life of your own	Having a job and getting out helps.
Time off	Having a holiday would help.
A decent income	The Government should recognise caring responsibilities.
Reliable and appropriate services of acceptable quality	Choice - some people would like someone coming in but I wouldn't want that. Somebody needs to come in and help with the chores - it makes such a difference. It's caring for you, taking some of the stress off you. What would improve things? Reliability and lateral thinking by people who go in, more attention to detail. Someone who can speak English at the end of the phone. Access to the service to be equal.

Desirable Outcomes	Comments made in the groups and interviews
Opportunities for the person cared for to have a good quality of life	Mother needs people to talk to of her own age, she needs stimulation. Look at the whole of him. Let him be in control. Being listened to and not patronised.
Better public attitudes towards people with disabilities or illness	The young to be educated about disability.

Factors which help and hinder achieving positive outcomes:

Desirable outcomes	Factors which help	Factors which hinder
Good access to information	Support from an informed advocate who also has access to service providers-examples: counsellor, District Nurse, worker from Advocacy Service. Information from carers groups and learning from other carers whom you meet. Learning to be assertive: " I used to be so nice and polite". Patience on the part of professionals in giving and repeating information	Feelings of helplessness, especially when coming to terms with a sudden diagnosis Failure of hospital staff to explain the personal and social consequences of medical conditions. "Nobody tells you unless you ask". Reluctance of medical staff to consider or explain alternative therapies/approaches. Poor co-ordination between services and support groups. Expensive telephone calls. Being unable to locate information: "The information is there but nobody will tell you where it is". Lack of direct access for the carer to the results of medical tests.

Desirable outcomes	Factors which help	Factors which hinder
Emotional support	Being in touch with others in similar circumstances. Knowing that there is someone to phone in an emergency, such as the GP. Counselling from someone who understands the condition of the person cared for. Particularly important in relation to mental illness. Often helpful if counselling involves the whole family. Having someone who knows about your own emotional needs and the conflicts which caring can engender.	Feeling isolated with the problem. Professionals assuming that you can cope and not taking notice of the signals that you can't.
Having a life of your own	Keeping a job and therefore another life promotes self-esteem and greater patience in managing the caring task.	Being unable to plan ahead for personal projects/holidays. The refusal of other members of the family to share the worry and the practical burden of caring.
Time off	Gradual introduction of cared-for person to facilities such as respite care or day care. It would be good if the carer was allowed to stay for the first few times. Sitting services provided at times when the carer can actually benefit from social contacts (e.g. Evenings/week-ends)	Negative attitudes on the part of the person cared for to help from outside. Unreliable transport which diminishes the benefit to carers of regular support services. Limited flexibility of sitting and Home care arrangements.

Desirable outcomes	Factors which help	Factors which hinder
A decent income	Paid employment and full access to benefits. Efficient Welfare Rights advice.	Sudden withdrawal of financial support when caring ends. Lack of recognition of time spent caring when calculating benefits and pensions entitlements. Delays in the claims procedure.
Reliable and appropriate services of acceptable quality	Appropriate housing. Fighting for quality services even at some personal cost to the carer.	Bureaucratic procedures and delays. Being fobbed off on the telephone. Telephone calls not returned. Promises made that are not kept.
Opportunities for the person cared for to have a good quality of life	Access to facilities, such as college courses and adult education classes, which encourage the development of skills and interests. But transport has to be adequate. Opportunities to receive independent counselling. Volunteers to undertake sitting or befriending.	Mixed hospital wards. Unreliable transport. Poor quality home care services.
Better public attitudes towards people with disabilities or illness	Education of young people.	Comments and harassment from neighbours or the general public.

3 b) Carers views on improvements needed in Southwark

In this section we have summarised the suggestions for improvements which carers made during the focus groups and interviews. We have also added points which were not specifically highlighted by the carers but which emerge from our analysis as issues to be considered in Southwark.

➡ *More contact with social workers*

The carers identified a need for easier access to social workers for general support and advice and also for more specialist social work support, for example in relation to learning disabilities and mental health.

There is considerable scope for improving access to social work services. Carers need to be able to make referrals for the person cared for and for themselves. There were many carers who felt that they had been fobbed off during their contact with the Social Services Department. Some had persisted and had had good experiences thereafter while some had given up altogether and now had very low expectations.

Once access has been gained carers would like more regular follow up visits and/or phone calls, with continuity of staff so that they do not have to explain their circumstances repeatedly.

Carers wanted to have confidence that back-up services would be available should they themselves be unable to care.

➡ *Developing the link between carers and the GP*

Some carers would like to turn to their GP for information, practical support and help in an emergency. In practice, the extent to which GPs were able to perform this supportive role appears limited by work pressures and also by a lack of awareness of carers' needs. There were nonetheless, good examples of awareness-building within GP practices which might provide models within the Borough.

➡ *A more outgoing approach to information provision*

Some carers believed that making information available in public places was not enough. They wanted to see information-givers adopting a more proactive approach, knocking on the doors of carers and talking to both the carer and the person cared for. They also pleaded for plain language and varied approaches to advertising services, for example through the use of videos. More generally, they felt that information should be freely given and that carers should not be made to feel demanding. Opportunities to talk to professionals from the same ethnic group as themselves were important to some carers.

Carers information needs were particularly crucial at the time when they start caring. They would like someone to play a keyworker or advocacy role in talking them through all the aspects of their caring role i.e. benefit entitlement, housing needs, as well as social and health care needs, and support in accessing services. They wanted help in making appointments and chasing up promised services. For some carers face to face contact is important but for others a telephone hotline would suffice.

➡ *A more consistent District Nursing service*

Carers considered that although individual staff were often excellent improvements were needed in the management and resourcing of the service in order to ensure that appointments were kept and that the standard of the service was made more predictable. They believed that more staff were needed in order to provide an appropriate level of care and attention to detail. The role of the District Nurse in linking with the carer and with other support services when problems arose, for example over the administration of medication, needed to be given more emphasis.

➡ *Other health services*

Better access to speech therapy services was needed. There seemed to have been problems over replacing staff and gaps in the service provision. Parents would also like speech therapy at home and in school holidays.

➡ *More active listening on the part of professional staff*

Being listened to with respect by professional staff was of primary importance to the carers. As with the provision of information, they felt that staff needed to be more active in seeking carers out and investigating their needs, particularly their needs for health care. They also emphasised the importance to the person cared for of being listened to in their own right.

Training of professionals should be improved to enhance their empathy with carers' situations. One carer said, *"It should be drummed into them that what is day to day for them is a personal tragedy for families".*

➡ *Better, more reliable transport*

Many carers described how their social lives and access to needed services and facilities were limited by inadequate transport. Existing subsidised transport schemes, such as Dial-a-Ride and the taxi-card scheme, were not offering the reliability and the rapid response which carers required. Transport was too often the missing link in their support system which limited access to the services and social contacts which they needed. Carers highlighted the stress and frustration which they experienced when services were in place but transport failed.

➡ *Reliable equipment*

Many depended upon equipment to help care for people with disabilities at home. They needed it to be delivered promptly and to be in working order. A number had experienced considerable problems over delays in delivery and faults which caused immeasurable frustration for themselves and the people cared for.

➡ *Home care services*

Home care services of a more consistently high quality were wanted, particularly where private agencies were used. Carers believed that staff should be more thoroughly trained in the tasks that were going to be required of them, such as lifting and using a hoist, and that new staff should accompany more experienced colleagues in order to learn the care needs of individual clients. Better time keeping, more professional attitudes and better value-for-money in terms of the time actually spent in the home were also requested. Lower charges for home care would enable some carers to have more help.

➡ *Respite care for children*

Parent carers of young children formed only a small minority of those who took part in the study. For these few carers, however, access to respite care emerged as a significant issue. The number of appropriate respite options was considered too limited to allow for rapid access and regular provision.

3 c) Other issues to emerge from the study

Our analysis of the material suggests that the following issues also deserve further consideration.

➡ *Improved access to community care assessments*

The assessment process worked well for many carers, providing practical outcomes and reassurance that they would not be allowed to drift unsupported. In a few cases, however, carers experienced unreasonable difficulty in obtaining an assessment at their own request and succeeded only with considerable persistence on their part. A more transparent and efficient procedure for responding to carers' requests is indicated.

More generally, many carers remain unaware of the assessment process and, as a result, are coping with minimal support for prolonged periods. **Carers of adults with mental health problems would appear to be particularly poorly informed**. Better education and publicity about the function of assessment and how to access it may be needed.

➡ *Stronger identification of carers' needs within the assessment process*

Community care assessments in Southwark remain strongly focused upon the person cared for, and carers have little understanding of the value of a separate assessment of their own needs or of their right to obtain it. This marginalisation of the carer seems to be reinforced by the assessment procedures and practice, in which the carer's needs are sometimes treated as an after-thought and not followed through. The feedback suggests that both social work staff and carers need to be convinced about the importance of carer assessments, and procedures reviewed to ensure that they form an integral part of the assessment process.

➡ *Improved liaison between services*

Poor liaison between services emerged as a general issue within the study but was particularly salient for carers of people requiring active medical treatment, where responsibility for that treatment was divided between primary care and hospital services. Carers felt confused about where to turn when problems arose, for example with an infection which failed to respond to treatment, and in some cases felt that appropriate treatment had been delayed because responsibility for medical care had not been clearly determined. This suggests that clearer lines of communication and contact procedures need to be established between carers and medical services, and between the services themselves

Appendix 1: Summary of Characteristics

	Gender		Age					Ethnic Origin						
	Male	Female	under 30	30 to 44	45 to 59	60 to 74	75+	White/ British	White/ Irish	White/ European	Black/ African	Black/ African Caribbean	Asian/ Bangladeshi	Prefer to leave blank
Focus Group Totals	1	12	0	3	3	4	3	11	1	0	0	0	0	1
Interviewee totals	13	26	0	13	14	9	3	27	4	1	3	2	2	0
GRAND TOTAL	**14**	**38**	**0**	**16**	**17**	**13**	**6**	**38**	**5**	**1**	**3**	**2**	**2**	**1**

	Marital Status					Relationship to carer							Gender	
	Married/ Permanent Relationship	Separated	Widow/ widower	Divorced	Single	Parent	Grand-parent	Brother/ Sister	Spouse	Son/ Daughter	Partner	Other	Male	Female
Focus Group Totals	6	1	1	0	5	6	0	1	4	3	0	0	5	9
Interviewee totals	24	2	0	3	10	13	0	2	11	9	5	1	17	24
GRAND TOTAL	**30**	**3**	**1**	**3**	**15**	**19**	**0**	**3**	**15**	**12**	**5**	**1**	**22**	**33**

	Age						Share same Household			Client Group					
	under 18	18 to 30	30 to 44	45 to 59	60 to 74	75+	Yes	No	Some-times	Older People (over 65)	People with physical disabilities	People with HIV/AIDS	People with learning disabilities	People with alcohol and drugs problems	People with mental health problems
Focus Group Totals	1	0	3	1	3	6	9	5	0	9	8	0	2	1	5
Interviewee totals	4	4	4	4	11	14	35	5	1	19	27	1	5	0	17
GRAND TOTAL	**5**	**4**	**7**	**5**	**14**	**20**	**44**	**10**	**1**	**28**	**35**	**1**	**7**	**1**	**22**